

In this pamphlet, you will find important questions you should ask of anyone who wants you or members of your family or community to be part of a research study.



For copies of this brochure:
CDC National Prevention
Information Network
1-800-458-5231

**For general information on protection
of humans involved in research
studies, please write to:**
National Institutes of Health
Office for Protection from
Research Risks
6100 Executive Blvd, Rm 3D01
Rockville, MD 20892-7507

Web sites of interest:
http://www.cdc.gov/nchstp/hiv_aids/dhap.htm (to download this brochure)
<http://www.hhs.gov/policy/>
<http://helix.nih.gov:8001/ohsr>
<http://www.bioethics.gov/>

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
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Taking Part in Research Studies: What Questions Should You Ask?

A research study is a way for finding answers to difficult scientific or health questions.

For example, scientists may want to understand more about how AIDS is spread by asking people about their activities in a survey.

Another example is when doctors might do a research study to find out whether a new medicine helps people improve their eyesight.



1. What is the study about?

- ✓ Why are you doing this study?
- ✓ Why do you want to study me or people like me? Who else is being studied?
- ✓ What do you want to get out of this study?
- ✓ What will you do with the results?
- ✓ Have you or others done this type of study ever before? Around here? What did you learn?

2. Who put this study together?

- ✓ Who is running or in charge of this study?
- ✓ Whose idea was this study?
- ✓ How were people like me part of putting it together?
- ✓ Who are the researchers? Are they doctors or scientists? Who do they work for?
- ✓ Have they done studies like this before?
- ✓ Is the government part of this study? Who else is a part of this study?
- ✓ Who is paying for this study?
- ✓ Who will make money from the results of this study?

3. How can people like me share their ideas as you do this study?

- ✓ How will the study be explained in my community?
- ✓ Who of people like me will look at this study before it starts?
- ✓ Who of people like me are you talking to as you do this study? A Community Advisory Board?
- ✓ Who from the study can I go to with ideas, questions, or complaints?
- ✓ How will people like me find out about how the study is going?

4. Who is going to be in this study?

- ✓ What kinds of people are you looking for? Why?
- ✓ Are you trying to get minorities in this study?
- ✓ Are you including people less than 18 years old?
- ✓ How are you finding people for this study?
- ✓ Is transportation and/or daycare provided for people in this study?
- ✓ Do I need to sign to participate?
- ✓ Will you answer all of my questions before I sign the consent form?
- ✓ Can I quit the study after signing the consent form? If I quit the study, will anything happen to me?

5. What will I get out of this study?

- ✓ What are the benefits?
- ✓ Is payment involved? How will I be paid?
- ✓ Will I get free health care or other services if I participate? For how long?
- ✓ Will I get general health care and/or psychological care if I participate? For how long?

6. How will I be protected from harm?

- ✓ Do I stand a chance of being harmed in this study? In the future?
- ✓ Does the study protect me from all types of harm?
- ✓ If I get harmed, who will take care of me? Who is responsible?
- ✓ If I get harmed in any way, will I get all needed treatment? Who pays for treatment?

7. How will my privacy be protected?

- ✓ Who is going to see the information I give?
- ✓ Will my name be used with the information?
- ✓ What happens to the information I gave if I quit the study?
- ✓ Is there a written guarantee of privacy?

8. What do I have to do in this study?

- ✓ When did you start this study? How long will it last?
- ✓ How much of this study have you already done?
- ✓ Have there been any problems so far?
- ✓ Will I get treated the same as everyone else?
- ✓ What kinds of different treatments are offered in this study? Is there a real and a fake treatment?

9. What will be left behind after the study is over?

- ✓ What will happen to the information people give? How will it be kept?
- ✓ What are you going to do with the results of the study?
- ✓ How will the public learn about the results? Will results be in places where the public can see them?
- ✓ Are you going to send me a copy of the results? When?
- ✓ What other studies are you planning to do here?